

# **The Last Year of Life in Europe:**

## **Regional variations in functional status and sources of support**

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**Abstract:** *Objectives* – To provide an initial account of the life circumstances of older Europeans in the year prior to death, focusing on regional variations in functional limitations and sources of support. *Methods* – We analyze 523 end-of-life interviews, collected as part of the Survey of Health, Ageing and Retirement in Europe (Wave 2), using logistic regression. *Results* – Functional limitations are spread fairly evenly across Northern, Central, and Southern Europe. Significant regional differences exist with regard to decedents’ main sources of support and location of death. Northern Europeans were least likely to receive help by their family only and most likely to be supported by non-kin. They also exhibited the highest risk to die in a nursing home. In Mediterranean countries, a pattern of exclusive family support and dying at home prevails. *Discussion* – Our findings support the notion of a ‘mixed responsibility’ of families and welfare states as providers of support for the elderly.

**Keywords:** end-of-life research; ADL limitations; social support; SHARE

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DESPITE talk about ‘broken limits to life expectancy’ (Oeppen & Vaupel, 2002) and evidence suggesting improvements in some dimensions of health in later life, including the immediate years prior to death (e.g., Liao et al., 2000; Parker & Thorslund 2007), the last year of life remains a particularly important and difficult period for the near-deceased themselves as well as for their families and health care professionals (see Romoren, 2003, for a comprehensive account). The year prior to death has been shown to be characterized by large increases in the propensity to experience significant cognitive and functional decline (e.g., Covinsky et al., 2003; Lunney et al., 2003), which constitutes a huge challenge to next-of-kin and professionals providing end-of-life care (e.g., Heyland et al., 2006; Imhof & Kaskie, 2008).

Over the past two decades, considerable evidence has been collected shedding light on various facets of older Americans’ last year of life, focusing on morbidity and disability in particular (see e.g., Bortz, 1990; Guralnik et al., 1991; Lentzner et al., 1992, for early studies), but also investigating patterns of religious practice and belief (Idler, Kasl, & Hays, 2001), for example. The number of European studies investigating the life circumstances of near-deceased, however, is rather limited yet (see e.g., Bickel, 1998, for Germany; Cartwright, 1992; Hanratty, Jacoby, & Whitehead, 2008, for Great Britain; Constantini et al., 2005, for Italy; Jakobsson et al., 2006, for Sweden). Moreover, to our knowledge no end-of-life research taking a cross-national perspective has been conducted so far. This should be particularly interesting, though, because previous research has identified significant variation in older people’s living conditions across the Continent (see Börsch-Supan et al., 2005, for a comprehensive overview), which one might also expect to see in the year prior to death.

Our study's focus is on regional variations in functional (i.e. ADL) limitations, sources of support (family vs. non-kin), and place of death. These issues are most relevant for the individuals concerned as well as for welfare states, which have to deal with increasing costs of (health) care in aging populations (e.g., Hogan et al., 2001; Rice & Fineman, 2004). Based on unique data from the Survey of Health, Ageing and Retirement in Europe (SHARE), whose second wave in 2006-07 included an end-of-life (or 'exit') interview for first wave respondents who died since baseline data collection in 2004-05, we follow the lives of older people from 11 Continental European countries right until the time of their death.

#### *Previous research*

Previous studies indicated considerable cross-country variation in older Europeans' physical health (including functional limitations) as well as in the provision of help by family members and non-kin. In addition to a socio-economic health gradient observed in all countries, there is clear evidence for a geographic health gradient suggesting that the older population in Southern Europe is more likely to suffer from physical health problems than their Northern European counterparts, despite a higher life-expectancy in the Mediterranean countries (e.g., Huisman, Kunst, & Mackenbach, 2003; Jürges, forthcoming; Mackenbach et al., 2005). These findings were further substantiated by a recent analysis of cross-national differences in older Europeans' grip strength, which is known to be a strong predictor of disability (Andersen-Ranberg et al., 2009).

A North-South gradient is also found when looking at patterns of support for the elderly. Support patterns are shaped by a complex interplay between the family and welfare state services in particular (e.g., Brandt, Haberkern, & Szydlik, forthcoming;

Glaser, Tomassini, & Grundy, 2004; Motel-Klingebiel, Tesch-Römer, & von Kondratowitz, 2005). Although family support plays an important role everywhere, the role of the family is more exclusive in the Mediterranean countries, whereas in Northern Europe help provided by the family is often complemented by professional services. This is also reflected in higher proportions of elderly people from Northern countries living in institutional households, such as old-age homes or long-term care facilities (e.g., Gaymu et al., 2006; Tomassini et al., 2004). Moreover, older Southern Europeans less often report an exchange of informal help with friends, neighbors, colleagues, or other acquaintances than their Northern counterparts (cf. Kohli, Hank, & Künemund, 2009).

No research has been conducted yet that addresses the geography of functional limitations and sources of support in older Europeans' last year of life. We do know, however, that a variety of socio-demographic characteristics are closely correlated with individuals' probability to suffer from functional limitations prior to death. Particularly age and sex turned out to be strong predictors of disability, with older people and women exhibiting the highest risks of experiencing functional limitations (e.g., Guralnik et al., 1991; Liao et al., 2000). Moreover, socio-economic differences in the health of near-deceased were detected (e.g., Cartwright, 1992; Palmore & Burchett, 1997). Because there is evidence for an association between marriage and health among the elderly (e.g., Goldman et al., 1995), studies should account for individuals' marital status as well (but see Lentzner et al., 1992). Both, socio-economic and marital status, are also important factors with regard to the provision of care and support in the last year of life (e.g., Grabbe et al., 1995; also see Broese van Groenou et al., 2006) – which

includes the issue of whether older people die at home or in an institution (e.g., Jakobsson et al., 2006; Klinkenberg et al., 2005).

## **METHODS**

### *Sample*

The analysis presented here is based on data from Wave 2 (Release 2.2.0) of the Survey of Health, Ageing and Retirement in Europe (SHARE), which was collected in 2006-07 (see Börsch-Supan et al., 2008, for a detailed description). The survey is modeled closely after the U.S. Health and Retirement Study and it is the first European dataset to combine extensive cross-national and longitudinal information on socioeconomic status, health, and family relationships of the older population. Wave 2 contains information on a representative sample of nearly 34,000 individuals aged 50 or older from 23,000 households in 14 countries, representing Europe's economic, social, institutional, and cultural diversity from Scandinavia to the Mediterranean. Eleven of these countries already participated in the 2004-05 SHARE baseline wave, contributing a total of 523 end-of-life interviews (for 287 men and 236 women).

Exit interviews were conducted with so-called proxy respondents. 80% of these were spouses or children (children-in-law, respectively) of the deceased. The remaining 20% were almost equally split across other family members and non-kin. 75% of the proxy respondents had daily contact with the deceased in the last year of his or her life, 13% reported to have had contact several times a week. Previous research showed that proxy respondents' assessments of physical health status, for example, exhibit a high level of reliability (e.g., Lawrence, 1995), thus making them not only an inevitable, but also trustworthy source of information for our study.

The average time between the decedent's death and the end of life interview was 14 months. Average age at death was 75.1 years among men and 80.8 years among women. One should bear in mind that our analysis of functional limitations and support in the last year of life is likely to be based on a somewhat positively biased sample (see de Luca & Peracchi, 2005, and Schröder, 2008, for details on overall survey participation and attrition in SHARE). *First*, almost all of our respondents were sampled from private households in 2004. With the currently available data we thus miss individuals who already lived in nursing homes in 2004 by the initial SHARE sample design (Klevmarcken, Hesselius, & Swensson, 2005; see Börsch-Supan et al., 2005: Chapter 2, for a detailed description of the SHARE baseline sample). *Second*, the fact that it was possible to find a person who was close enough to the first wave respondent and willing to share information about a recently deceased relative, neighbor or friend implies that we may miss information on individuals without close relatives or friends nearby. Overall, exit interviews were realized for 83% of baseline respondents whose death is confirmed.

### *Measures*

We consider three outcomes in our analysis: functional status, sources of support, and place of death. *Functional status* in the year prior to death was measured by the individual's ability to perform activities of daily living (ADLs) without difficulty. Proxy respondents were asked to report only such ADL difficulties, which lasted at least three months in the decedent's last year of life. Building on the capacity to dress, walk across a room, bathe, eat, get in or out of bed, and use the toilet, we distinguish three groups of decedents: 'fully functional' (no limitation), 'moderately restricted' (limitations in one to five ADLs), and 'severely restricted' (limitations in all six ADLs).

If the proxy respondent reported that the decedent suffered from one or more ADL limitation, a follow-up question was asked providing us with information about the main *sources of support* with ADLs. We collapsed the original answer categories into three groups of helpers: ‘family only’ (spouse, children, other relatives), ‘non-kin only’ (professionals, volunteers, friends or neighbors), and ‘family & non-kin’ (note that multiple answers were allowed). Finally, we exploit information on the decedent’s *place of death*, where we distinguish three different settings: ‘outside of an institution’ (usually at one’s own home), ‘hospital or hospice’, and ‘nursing home’ (including residential homes or sheltered housing).

In the multivariate analysis, we accounted for a set of standard socio-demographic *control variables* (all measured at baseline): age (50-74, 75-84, and 85 years or older), sex, the highest educational degree ever achieved (‘low’ = lower secondary level of education or less; ‘medium’ = upper secondary or post-secondary, non-tertiary level of education; ‘high’ = first stage of tertiary education or higher), and marital status. Our primary interest, however, was in regional variations. Because of the yet relatively small sample of decedents in the SHARE study, countries were grouped into three *regions* to maintain sufficiently large numbers of observations for the analysis: North (Denmark, Sweden, and the Netherlands), Central (Austria, Belgium, France, Germany, and Switzerland), and South (Greece, Italy, and Spain).

### *Analysis*

In addition to simple cross-tabulations of our three outcome measures by region, we estimated ordered and multinomial logit models (using STATA 10.0), controlling for the socio-demographic variables described above and region. The results of the multivariate models are presented as odds ratios. – Note that we applied effect coding to

highlight each region's deviation from the grand mean of all regions in the sample. Effect coding uses contrast weights that result in tests of deviations of group means from the intercept coefficient, which inherits the value of the grand mean.

## **RESULTS**

### *Descriptive findings*

On average, and with barely any regional variation, 40% of the deceased SHARE baseline respondents were fully functional (in terms of ADL limitations) in their last year of life; see Table 1a. Moderate restrictions were reported in a similar order of magnitude, but here we detect larger regional differences: in the Northern countries, 45% of the dead suffered from up to five ADL limitations in the year prior to their death, whereas only 32% of their Southern European counterparts experienced moderate restrictions. When turning to 'severe restrictions', we observe a reversed North-South gradient: compared to the Scandinavian countries and the Netherlands (15%), nearly twice as many decedents in Greece, Italy, and Spain were limited in six (or more) ADLs.

Almost all decedents (97%) who suffered from functional limitations received help with ADLs from at least one person. Overall, the most frequently named providers of help clearly were family members (children in particular); details not shown. However, the family is often supported by non-kin helpers (especially professionals); see Table 1b. In Northern Europe, only one in four decedents receiving help with ADLs relied on family support only, whereas almost half received joint support from family and non-kin helpers. Exclusive family support is much more widespread in the Mediterranean countries (72%) and – to a lesser degree – in the 'Central' region (61%).



But even here, the role of non-kin helpers is substantial and the proportion of near-deceased relying on non-kin as the only source of support with ADLs (10-11%) is anything but negligible.

About half of our sample of dead SHARE baseline respondents deceased in a hospital (or hospice); see Table 1c. Regional differences in people's place of death are mainly observed when comparing the proportions of decedents who died outside of an institution or in a nursing home, respectively. In Northern Europe, almost equally large shares of people died at home (29%) or in a nursing home (26%). In the South, however, 50% of the respondents deceased at home, whereas only 5% were reported to have died in a nursing home. With regard to the distribution of deaths across different locations, the 'Central' countries – Austria, Belgium, France, Germany, and Switzerland – take an intermediate position.

[Table 1 about here]

### *Multivariate results*

The results of the ordered logit model for decedents' *functional status* (see Table 2) confirmed findings of previous research by indicating a significant effect of age and sex on individuals' probability to suffer from ADL limitations in their last year of life: particularly the oldest old (OR = 2.29\*\*) and women (OR = 1.80\*\*) exhibited an increased risk to be moderately or severely restricted. Education and marital status, however, did not bear statistically significant associations with functional status in the year prior to death. The same was true for our three regional indicators, whose coefficients did not indicate any significant variations from the grand mean.

[Table 2 about here]

Turning to the multinomial logit model for *sources of support* (see Table 3a) we found no evidence for differences in the main sources of help with ADLs according to socio-demographic characteristics (the smaller risk of married decedents to rely exclusively on non-kin support being the only exception). Region, however, does play a major role in determining whether family, non-kin, or both provided help in people's last year of life. Compared to the grand mean, Northern Europeans were significantly more likely to receive support from non-kin only (OR = 3.50\*\*) or to be helped jointly by family and non-kin (OR = 3.25\*\*), whereas the reverse was true for Southern Europeans (OR = 0.51\* and 0.36\*\*, respectively). In the 'Central' region, the odds of receiving exclusive non-kin support vis-à-vis exclusive family support (OR = 0.56\*\*) was similar to the Mediterranean, whereas the probability to be helped by family and non-kin together was not significantly different from the reference group.

[Table 3 about here]

Regarding the decedents' *place of death*, we found that baseline respondents who died at age 75 or over (OR, 75-84 = 2.42\*; OR, 85+ = 3.12\*) and women (OR = 2.68\*\*) were most likely to die in a nursing home; see Table 3b. The probability to die in a hospital (vis-à-vis dying at home), though, did not vary systematically across individuals exhibiting different socio-demographic characteristics. However, we do observe – again – significant regional differences with above average odds of dying in a nursing home for residents of Denmark, Sweden, and the Netherlands (OR = 3.48\*\*), whereas Greeks, Italians, and Spaniards were least likely to die in an institution (OR, hospital = 0.66\*\*; OR, nursing home = 0.28\*\*).

## DISCUSSION

This study provided an initial account of the life circumstances of older Europeans in the year prior to their death, focusing on regional variations in functional limitations and sources of support. Exploiting information from ‘exit’ interviews with proxy reporters for deceased baseline respondents of the Survey of Health, Ageing and Retirement in Europe, our analysis showed a high prevalence of moderate or severe ADL limitations in the last year of life. The good news is that basically all decedents who were restricted received support by family and/or non-kin helpers.

A multivariate analysis confirmed findings of previous – mainly U.S. – studies regarding the role of age and sex in determining the functional status of near-deceased. However, the oldest old and women were not only most likely to suffer from ADL limitations; they also exhibited the highest risks of dying in a nursing home. While functional limitations seemed to be spread fairly evenly across regions – North, Central, and South – in Continental Europe, we observed significant regional differences with regard to the main sources of support in people’s last year of life and their place of death (even after having controlled for differences in socio-demographic characteristics). Northern Europeans were least likely to receive help with ADLs by their family only and most likely to be supported by non-kin (with or without additional help by family members). They also exhibited the highest risk to die in a nursing home. The reverse is true in the Mediterranean countries, where we observed a predominant pattern of exclusive family support and dying at home.

These findings are consistent with other European research suggesting the existence of different ‘regimes’ of help and care across the continent as well as a ‘mixed responsibility’ of families and welfare states as providers of support for the elderly (cf.

Brandt et al., forthcoming; Motel-Klingebiel et al., 2005). They also have implications for public policies. Although long-term care needs may not parallel demographic projections (Parker & Thorslund, 2007) future decades will impose further demands on both families and professionals supporting the elderly as they approach their end of life. To master these challenges, joint forces are necessary. The experience of the Danish home care policy, for example, provides evidence that community-based services can aid family caregivers, enable frail elderly to live in the setting of their choice, and be cost-effective from a public policy perspective (Stuart & Hansen, 2006; see Grabbe et al., 1995, for related evidence from the US)

However, although home seems to be the preferred place of death for the majority of elders (e.g., Beccaro et al., 2006), there is some evidence for a shift in people's location of death from the community to institutions, especially due to a rising number of oldest-old women and men (e.g., Ahmad & O'Mahony, 2005). To meet the growing end-of-life needs in hospitals and nursing homes, which are likely to result from such a development, should pose a particular challenge to Southern European countries. Different from the Northern European 'weak-family societies', the Mediterranean societies still have a tradition of 'strong' families and thus seem least prepared – in terms of their institutional infrastructure – for the consequences of population aging (see, for example, Reher, 1998).

While this analysis of SHARE exit interviews already provided new insights into the geography of functional status and sources of support in Continental Europe, its scope is still limited in various ways. *First*, due to the initial SHARE sampling design, we currently miss individuals who already lived in nursing homes in the baseline wave. Future waves of SHARE, however, will allow investigating end-of-life experiences in

nursing homes along the lines of recent U.S. research (e.g., Munn et al., 2008; Wetle et al., 2005), as study participants moving into nursing homes will be tracked. *Second*, the yet small number of observations precluded a fully-fledged investigation of cross-national differences in the life circumstances of the near-deceased. This will change, however, once further waves of SHARE become available (cf. Börsch-Supan et al., forthcoming). These will provide us not only with a greater number of exit interviews, but also with more opportunities to link respondents' end-of-life experiences with detailed information from previous interviews. Only then will the research potential introduced in this article fully unfold.

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## Tables

Table 1: Regional variations<sup>a</sup> in decedents' functional status, sources of support, and place of death

Percentage of decedents by ...	<i>North</i>	<i>Central</i>	<i>South</i>	Total
<i>(a) Functional status (ADL)</i>				
Fully functional	40	42	39	40
Moderately restricted	45	35	32	37
Severely restricted	15	23	28	23
<i>(b) Sources of support with ADLs</i>				
Help provided by family only	27	61	72	55
Help provided by non-kin only	27	10	11	15
Help provided by family & non-kin	46	29	17	29
<i>(c) Place of death</i>				
Died outside of an institution	29	36	50	39
Died in a hospital or hospice	44	54	45	48
Died in a nursing home	26	10	5	13

Notes: <sup>a</sup> *North* = Denmark, the Netherlands, Sweden. *Central* = Austria, Belgium, France, Germany, Switzerland. *South* = Greece, Italy, Spain. Source: SHARE Wave 2 (Release 2.2.0), authors' calculations.

Table 2: Ordered logit model for functional status (ADL)<sup>a</sup> in decedents' last year of life – odds ratios (95% confidence intervals)

<i>Socio-demographic characteristics (Wave 1)</i>	
Age 50-74 <sup>b</sup>	1.00
Age 75-84	1.43 (0.97 - 2.11)
Age 85+	2.29** (1.45 - 3.62)
Female	1.80** (1.26 - 2.58)
Low education <sup>b</sup>	1.00
Medium education	0.80 (0.52 - 1.23)
High education	0.71 (0.40 - 1.28)
Married	1.35 (0.94 - 1.95)
<i>Region<sup>c</sup></i>	
North	0.90 (0.71 - 1.14)
Central	1.00 (0.79 - 1.26)
South	1.11 (0.88 - 1.41)
<i>Cut points</i>	
Cut point 1	2.34* (1.17 - 4.69)
Cut point 2	12.79** (6.18 - 26.49)
Log likelihood	-535.7
Observations	517

Notes: <sup>a</sup> Three categories: fully functional (base category), moderately restricted, severely restricted. <sup>b</sup> Reference category. <sup>c</sup> Effect coding. \*\* Significant at 1% level. \* Significant at 5% level. Source: SHARE Waves 1 & 2 (Release 2.2.0), authors' calculations.

Table 3: Multinomial logit models for (a) sources of support with ADLs during the last year of life and (b) place of death – odds ratios (95% confidence intervals)

	(a) Sources of support with ADLs:		(b) Place of death:	
	Family only <i>versus</i> ...		Outside of institution <i>versus</i> ...	
	Non-kin only	Family & non-kin	Hospital / hospice	Nursing home
<i>Socio-demographic characteristics (Wave 1)</i>				
Age 50-74 <sup>a</sup>	1.00	1.00	1.00	1.00
Age 75-84	2.34	0.89	0.72	2.42*
	(0.87 - 6.30)	(0.44 - 1.81)	(0.46 - 1.13)	(1.02 - 5.76)
Age 85+	1.79	1.23	0.64	3.12*
	(0.61 - 5.28)	(0.56 - 2.69)	(0.37 - 1.11)	(1.22 - 7.97)
Female	1.88	1.40	0.93	2.68**
	(0.80 - 4.39)	(0.75 - 2.62)	(0.61 - 1.42)	(1.31 - 5.51)
Low education <sup>a</sup>	1.00	1.00	1.00	1.00
Medium education	1.07	0.78	0.52*	1.18
	(0.38 - 3.05)	(0.36 - 1.67)	(0.31 - 0.87)	(0.52 - 2.65)
High education	1.50	0.41	1.05	0.55
	(0.45 - 5.01)	(0.13 - 1.32)	(0.54 - 2.07)	(0.16 - 1.91)
Married	0.32*	0.72	1.20	0.53
	(0.13 - 0.80)	(0.37 - 1.39)	(0.78 - 1.84)	(0.25 - 1.09)
<i>Region<sup>b</sup></i>				
North	3.50**	3.25**	1.20	3.48**
	(2.07 - 5.92)	(2.11 - 5.00)	(0.88 - 1.64)	(2.23 - 5.41)
Central	0.56*	0.85	1.26	1.02
	(0.32 - 0.97)	(0.58 - 1.26)	(0.95 - 1.66)	(0.64 - 1.62)
South	0.51*	0.36**	0.66**	0.28**
	(0.30 - 0.87)	(0.24 - 0.55)	(0.50 - 0.88)	(0.16 - 0.49)
Constant	0.10*	0.46	1.83	0.04**
	(0.02 - 0.60)	(0.13 - 1.64)	(0.81 - 4.12)	(0.01 - 0.18)
Log likelihood		-254.8		-445.1
Observations		299		503

Notes: <sup>a</sup> Reference category. <sup>b</sup> Effect coding. \*\* Significant at 1% level. \* Significant at 5% level. Source: SHARE Waves 1 & 2 (Release 2.2.0), authors' calculations.